COLLABORATION

AMONG FAMILIES, EARLY
INTERVENTION PROGRAMS,
AND SPECIALTY PROVIDERS

**A project of the Low Incidence Committee
of the Early Intervention Interagency
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This document is designed to improve collaboration among service providers to children with low incidence conditions ("Specialty Service Providers"), Early Intervention programs, and families. The following low incidence conditions fit the criteria for specialty services:

- Blindness
- Visual Impairment
- Deafblindness
- Deafness
- Hearing Loss
- Autism Spectrum Disorder/Autism/ Pervasive Developmental Disorder

Low incidence providers are also known as Specialty providers. They are professionals in Early Intervention programs, in specialty programs, or in private practice who have been specifically trained and/or credentialed to address the needs of children with low incidence conditions.

The goal of collaboration is to use the combined knowledge and skills of all providers as well as of families in the most effective way in order to develop comprehensive and appropriate programs for children with low incidence conditions. The following are suggested guidelines for ongoing collaboration among families, Early Intervention programs and Specialty providers.

Entrance To/Exit From EI Services

A child may be referred to Early Intervention services with or without a clear diagnosis. When Early Intervention staff obtain a developmental history on a child and his/her family during intake, it is important to be aware of high risk factors for low incidence conditions. Evidence of high risk factors can indicate the need for further assessment and possible collaborative intervention with specialty providers. Behavioral indicators, as reported by parents or noted from interactions with the child, also need to be considered so that a recommendation for testing can be made as early as possible. Specialty providers know about appropriate diagnostic testing centers and medical specialists who work with children with low incidence conditions. Recommendations should be shared with the service coordinator at the Early Intervention program , who is responsible for making sure that appropriate procedures will be followed to involve the child's primary care physician and to secure any pre-authorizations required by health insurers.

Refer to the EI Specialty Services section of the Early Inte rvention Policy Book for brochures describing high risk and/or behavioral indicators for *low incidence conditions:*

- *" Is your child developing in ways that puzzle you?"*
- *"Do you think your child has a vision loss?"*
- *"If you think your child has both a vision and hearing loss"*
- *"How well does your child hear?"*

Referral

Referrals are made either to the Early Intervention program or directly to the Specialty Provider from sources such as hospitals, pediatricians and parents. Cross referral is then critical - Early Intervention program to Specialty Service provider and Specialty Service provider to Early Intervention program - to insure timely assessment and development of the Individualized Family Service Plan (IFSP). Since there are a range of intervention t echniques and Specialty Service Provider program types, parents need to be given "informed choice" of program options. Agencies such as the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH), the Massachusetts Commission for the Blind (MCB), and Autism Resource Centers may have additional information about resources for families of children with low incidence conditions. Specialty providers and/or agencies may be helpful in working with families to define the range of service option choices. Refer to the EI Specialty Services section of the

Early Intervention Policy Book for program specific information and Low Incidence brochures.

Eligibility Evaluation

The eligibility evaluation should include consideration of risk factors relative to:

- vision
- hearing
- behavioral indicators for autism/PDD

If any of the above risk factors is identified, a discussion should occur with the family about the need for further diagnostic testing, initiating the assessment process and, as appropriate, sharing information about specialty providers and relevant state agencies.

Assessment

Assessment consists of those on-going procedures used by appropriate qualified personnel throughout the period of a child's eligibility for early intervention services to identify:

(1) the child's unique strengths and needs and the services appropriate to meet those needs and

(2) the resources, priorities and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler.

The assessment emphasizes the collaborative process among Early Intervention personnel, the family, and other agencies and providers. Scheduling should be primarily responsive to family and child needs and preferences regarding time, place and other such factors. Families shall be given prior written notice of assessments. The notice will include the voluntary nature of the consent. (*Early Intervention Operational Standards, VI.E.1 -2, July 2003)*

Collaboration among the family, the Early Intervention provider and the Specialty provider is important throughout the assessment process. The Specialty provider staff person can either act as a direct participant by assessing the child in his/her particular area of expertise, or as a facilitator or consultant by observing testing to point out when the low incidence condition impacts the testing or unfairly affects the scoring and requires some modifications. Being part of the assessment team is beneficial to both the Early Interventio n staff and the Specialty provider staff. When team members share their respective areas of expertise, a true multidisciplinary evaluation may be achieved. Both the Early Intervention staff and the Specialty provider should contribute to the writing of t he assessment report.

If the Specialty provider is unable to be present during the team assessment, the appropriate specialist can do an assessment at a separate time. Examples include a deafness specialist evaluates the communication skills of a child who is deaf, a vision specialist evaluates the impact of blindness on a child's cognitive

skills, or a behavioral specialist assesses social/behavioral skills of a child with possible PDD/Autism.

Individualized Family Service Plan (IFSP)

Early Intervention programs are encouraged to develop service options using an outcome-driven model. Service recommendations are based on a thorough analysis of child and family priorities. A child's developmental profile does not automatically translate to a particular type, level, or frequency of intervention. Accountability is measured by whether outcomes achieved beyond specific disciplinary goals effectively address the child's and family's functioning at home, in play, and while learning. An outcome-driven approach includes promoting a child's abilities, modifying the environment, providing resources and/or adapted equipment, revising schedules and routines, developing new skills and behaviors of key adults in the child's life, and reframing adult perspectives and expectations of the child.

Specialty providers are encouraged to participate in the team process of assisting family members to prioritize outcomes and address a limited number of outcomes at a time. This model often emphasizes sequential, rather than simultaneous, services and time-limited service recommendations.

The IFSP includes services to be provided by the Early Intervention program and the Specialty provider. The Early Intervention program and Specialty provider

staff, as well as other personal and/or professional services invited by the family, should be actively involved with the family in the IFSP process to determine services. The initial referral to a Specialty provider may be indicated on the Outcomes and Strategies page of the IFSP. The plan for ongoing services to be provided by a Specialty provider should be specified on the Service Delivery Plan page. Early Intervention Service Coordinators should work with the parents and the Specialty provider to determine the appropriate amount and type of low incidence services. Specialty providers need to contact EI Service Coordinators when they propose a change in the Service Delivery Plan or when they anticipate a significant change or interruption in the existing IFSP.

Services

Services may be delivered in a variety of settings and styles to reach child and family outcomes. Some examples of services are home visits, center visits, child groups, and parent groups.

The intent of the Individuals with Disabilities Education Act (IDEA) is to provide family-centered, community-based services that support the inclusion of children with disabilities and their families into all aspects of community life. This means that Early Intervention program and Specialty providers need to justify on the IFSP any time a child is to be served in what is not considered a natural setting. Parent choice of a particular setting is not considered to be sufficient justification for providing services in segregated settings. This is an individualized process .

A natural environment should not be thought of as a place or location, but as a process of individually planning with a family about where a child would be spending time in the community if he/she did not have special needs.
Early Intervention program staff talk with a family about the needs of their child, the outcomes they would like to see achieved, and how all service providers can help the family address those needs. A child with a low incidence condition may need to participate in a continuum of services to achieve desired outcomes. If the provision of service in specialized settings is justified based on clinical needs and outcomes, a child's participation in such settings must be re-evaluated on an ongoing basis. A plan for the transition into a more natural setting needs to be included in the IFSP.

Specialty providers are expected to strive for opportunities for inclusion and to provide services to a child in a natural environment. This does not mean that families cannot network with other parents of children with like disabilities or that children can never be served in specialized settings. It does mean that any such service options be offered on an individualized basis that is developed in response to clinical need and may be time limited.
(References: "Community-Based Care: Providing Comprehensive Early Intervention Services to Children in Natural Environments," May 1998, MDPH document; "Enhancing Early Intervention," March 1999, MDPH document.)

Specialty providers may assume a variety of service roles to help achieve child and family outcomes: consultants to Early Intervention staff/family, direct service providers, facilitators for parent-to-parent contacts, developmental monitoring in their area of expertise, and/or assistance with transition planning. Specialty providers may offer a family the chance to meet "role models" (i.e., older children and/or adults) with low incidence conditions to offer some sense of future developmental opportunities for their child.

Collaboration and communication among the family, the Early Intervention team, and the Specialty provider are essential to assure clear assignment of roles and optimal child development. For example, in determining roles, the Specialty provider, from the start or as transition nears, may be identified as the primary direct service provider. It is critical that the Specialty provider and Early Intervention Program service coordinator be in close, regular contact to keep each other informed about progress and concerns, needs for changes in services, scheduling for assessments, transition planning meetings, etc. This contact may take place through sharing of session notes, regular telephone calls, and co-treatment. (See Appendix A for recommended staff guidelines for Early Intervention programs and Specialty Providers serving the same family.)

Transition

As the child approaches age three, the family, the Early Intervention provider, the Specialty provider, and the Local Education Agency (LEA) play an important collaborative role in:

- assisting to define the special educational needs of the child
- outlining program components that will help the child succeed in a preschool program
- visiting and/or identifying potential programs
- determining agencies or resources which might contribute to the transition process and planning with the family.

Early Intervention program and Specialty provider staff should be available to attend meetings with school districts and parents and give input into the development of the Individualized Educational Plan (IEP).

ADMINISTRATIVE CONSIDERATIONS

Contractual Relationships

I. The Massachusetts Department of Public Health has a direct contractual relationship with some specialty service providers. Early Intervention programs do not need to subcontract with these providers, nor do they need to apply for Provisional Certification of the staff of these specialty service providers in order to make their services available to families. An approved program bills the Department of Public Health directly. These programs include:

- Perkins School for the Blind (includes New England Center for Deafblind Services)
- Massachusetts State Association for the Deaf : Family Sign Language Program
- Providers of intensive programs to children with Autism Spectrum Disorders:

BEACON	LEAP Program
Building Blocks	The May Center
Children Making Strides	New England Center for Children
Educational Consultants of New England	Pediatric Developmental Center
HMEA	The REACH Program

II. Early Intervention programs may contract directly with Low Incidence providers who work as private consultants or who are part of agencies. Such providers have been specifically trained in the spec ial skills and knowledge to work with children with Low Incidence conditions and their families. Services to children who are deaf/hard of hearing are frequently secured this way. Information about such Specialty providers is available in the EI Specialty Services section of the Early Intervention Services Policy Book.

III. Early Intervention programs with staff who are appropriately credentialed to meet low incidence needs are under no obligation to subcontract with private consultants. The list of Low Incidence providers varies from region to region and changes often. When an Early Intervention program is contracting with a Specialty provider who does not have a contractual relationship with DPH, it needs to:

- set up subcontracts with the Specialty prov iders that clarify paperwork and billing responsibilities; and
- apply for Provisional Certification for any subcontracted staff

Staff Certification

All individuals who provide Early Intervention services within the Commonwealth must meet one of the three levels of certification of Early Intervention Specialist, the certification for professional practitioners that requires competency in all

areas of Early Intervention practice. The three levels of certification are described in the Massachusetts Early Intervention Operational Standards. At this time, Provisional Certification is sufficient for Specialty providers working twenty hours or less in Early Intervention programs. Applications for Provisional Certification as Specialty Service providers should be sent to the Director of The Office of Specialty Services at the Department of Public Health.

Components of Collaboration

Scheduling

Early Intervention programs should endeavor to include Specialty providers in assessments, IFSP development, and team meetings related to transition. Advance notice and negotiation around scheduling of such events is recommended.

Record Keeping

Record keeping needs to be consistent with Early Intervention Operational Standards. Progress notes, assessment reports, and billing forms must be submitted to Early Intervention programs in a timely way to ensure compliance with Early Intervention Operational Standards billing guidelines and with Early Intervention individual agency billing requirements.

Service Delivery

Early Intervention programs are regularly monitored to ensure that services specified on the IFSP are delivered. When it is necessary for a Specialty provider to change, delay, or otherwise interrupt the provision of service specified on the IFSP (or expected by the family if the IFSP process has not been completed), it is incumbent upon the Specialty provider to notify the Early Intervention service coordinator of the change.

Specialty providers function as part of the IFSP team, not as independent consultants. Any recommendations that affect the IFSP, such as changes in the type or frequency of service or requests for additional referrals/consultations, need to be discussed with the Early Intervention service coordinator (who acts as liaison to the IFSP team). It is expected that children served by Specialty providers will remain active in their Early Intervention programs, with the extent of involvement varying depending upon child and family needs. The Early Intervention program is responsible for coordinating transition to the Local Education Authority (LEA), which should involve the active participation of Specialty providers.

(Reference: Policy on Early Childhood Transitions, Early Intervention Services Policy Book.)

Co-treatment

Co-treatment visits of Specialty providers and Early Intervention staff are encouraged to improve collaboration and for cross-training purposes. Co-treatment visits may occur as often as is clinically appropriate between Early Intervention program staff and approved specialty service providers in programs that contract directly with the Department of Public Health without any need for clinical waivers (see the list in Section I). Frequency of co-treatments for other Specialty providers must conform to the Department of Public Health standard of one co-treatment per month per child, unless a waiver justifying the extraordinary circumstance is granted.

Waivers

If the IFSP team agrees that some variation in clinical approach that falls outside of the boundaries of the Early Intervention Operational Standards is appropriate for a particular child, the Early Intervention program may apply to DPH for a clinical waiver for this service.

Sharing Of Documents and Appropriate Releases

Collaboration involves sharing reports and documents as well as face-to-face clinical meetings. Early Intervention programs and Specialty providers need to arrange for the timely exchange of assessment reports, IFSPs, and progress/clinical notes. Family approval for such exchanges must be obtained in advance via release of information forms.

APPENDIX A

GUIDELINES FOR STAFF OF EIPs and SSPs SERVING THE SAME FAMILY

Goal: convey to family that <u>all</u> providers are contributing to a comprehensive service plan for the child and family

- Avoid adding to the family's stress
- Avoid adding to the provider's stress

Principles:

1. **Speak respectfully about other providers**
   - Do not disparage other programs or techniques even if you do not agree with their approach – use neutral language in any discussions
   - Highlight the fact that there are different ways to teach any one skill, that you use one way; other programs use others; there are even other strategies that might be used
   - Avoid getting pulled into discussions with families about other providers. Encourage the family to contact the supervisor in the other program with their concerns.

2. **If the family or provider has concerns about what a staff person from another program is doing**
   - Share your concern with your supervisor, who will decide if the concern warrants contacting the other staff person's supervisor
   - Do not share your concern with the family – supervisors have a communication system among agencies that should be utilized
   - When families raise concerns, refer them to the other agency's provider and/or supervisor

3. **Scheduling of sessions should not be a competitive process**
   - Scheduling conflicts should be addressed by program supervisors
   - Requests for changes in schedules should be addressed to supervisors
   - Do not encourage a parent to cancel another provider's scheduled timeslot to accommodate your availability

4. **Programs should be open about sharing their goals and techniques**
   - Avoid contributing to the dynamic that any one program knows best and should dictate what a child needs
   - Set up a protocol for getting staff together to review goals – the child specific data should be used in decision making

- When families ask questions about another program's goals and techniques, refer them to the provider and/or supervisor of the other program

5. Specialty Service providers need to:

- Let EIPs know about referrals of children in their programs that come from other sources
- Confer with service coordinator when SSP services begin, discuss planned service intensity so it can be incorporated in I FSP
- Confer with EI service coordinator about any changes in the service plan (these need to be incorporated in the IFSP)
- Offer to participate in future assessments, IFSP reviews, and transition planning